

## Cassandra's story: Sparing a limb, saving a child

After sitting still through the long drive from Spokane to Seattle, ten-year-old Cassandra Burris is springing around on her long legs, jumping from a bench in a park-like courtyard of Children's Hospital and Regional Medical Center. Still, it comes as a bit of a surprise when Cassandra's mother Carol remarks that her daughter "likes to play basketball with the boys."

Cassandra pulls up her jeans leg as far as it will go, revealing just part of a scar that runs the length of her right femur. Already, she's a veteran of more medical procedures than many adults require in a lifetime: two rounds of chemotherapy and four surgeries, including two transplants of donor bone grafts.



*Cassandra Burris after  
her bone transplant*

Cassandra was just six when she was diagnosed with Ewing's sarcoma in her right femur. Only 20 years ago, amputation would have been the sole treatment option. In 1999, Northwest Tissue Center Medical Director Dr. Ernest "Chappie" Conrad, a specialist in limb-sparing surgeries in pediatric oncology cases, resected the tumor and transplanted a donor bone graft from the Tissue Center, in the first step of a successively staged surgical plan that will culminate when Cassandra reaches 14, the age at which girls typically stop growing.

Dr. Conrad is the director of the Pediatric Bone Tumor Clinic at Children's Hospital and Regional Medical Center and professor and interim director of the Orthopedics and Sports Medicine Department at the University of Washington Medical Center. He explains the surgeries on [page 2](#).

Only about 25 percent of Ewing's sarcomas occur in a child as young as Cassandra was at diagnosis; the disease more typically occurs around age 14. Pediatric patients like Cassandra present particular rewards and challenges because, if the tumor has progressed too far into the joint, saving a limb often involves interfering with a growth plate, in Cassandra's case, in the distal femur. The challenge then is to provide for normal growth so both legs are close to the same length by the time a teenager reaches his or her full height.

"Losing a bony segment involving a growth plate saves the knee joint, but now we need to make her grow," explains Dr. Conrad.

"The good thing is that young kids do well tumor-wise," he adds, "but in Cassandra's case, growth is a huge issue."

## Sports, sports, sports

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Cassandra loves books—the Goosebumps series is a favorite—and reading is her favorite subject in school. Like any kid, she has a stack of beloved videos as well, with *The Parent Trap* and *Willie Wonka* near the top.

But on the day of her appointment with Dr. Conrad, her mind is on sports. She's excited that after the visit, she's headed to a Seattle Mariners' game with the \$20 bill her grandfather gave her to spend at Safeco Field. Yes, she likes to play softball, but it seems another sport is her favorite.

"Hockey, I want to play hockey," Cassandra says. "I love the Chiefs, Spokane's team."

OK, then, just for the record, what does she think of dresses?

"I DON'T like wearing dresses. I'm a tomboy, that's for sure."



*"You don't realize how important donation is until you face something like this yourself. It's such an incredible gift." – Carol Burris, Cassandra's mother*

## More than growing pains

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Carol Burris recalls that Cassandra began complaining of pain in her right leg at the age of six. When she got a call from Cassandra's school, saying that her daughter had cried all day because of the intense aching in her leg, Carol knew the problem had to be something more serious than the growing pains diagnosed by the doctor. Cassandra's pediatrician suspected juvenile rheumatoid arthritis.

After an X-ray and blood tests, Carol had expected to call back in a few days to confirm this diagnosis. Instead, the doctor's office advised her to come in without Cassandra, and to bring another adult.

Carol recalls the drive to the pediatrician's with her mother. "What's the worst case scenario?" Carol asked. "My mom said, 'cancer. It's a grandmother's instinct.'"

"It was devastating. I didn't know anything about childhood cancer. I thought, 'My child is going to die.'"

The Burris family was referred to Dr. Judy Felgenhauer, a Spokane oncologist, who scheduled an MRI and then referred Cassandra to Dr. Conrad in Seattle, who performed a biopsy. Before surgery, Cassandra underwent her first round of chemotherapy.

Cassandra's memory of chemotherapy is less traumatic than her mother's: "It was fun in the hospital when I could grab my hair and pull it out." Soon, of course, Cassandra had to have her head shaved. "I like my hair now," she's quick to add.

"Cassandra was very sick during chemo," says Carol. "When she was up, everybody was up and when she was down, everybody was down."

When Cassandra was back at home, however, it became clear that there were complications; the rod was slipping into her knee. She had additional surgeries in June and August, 2000; Carol remembers that finally in April, 2001 “she became a total child again. She was walking without the walker, riding her bike, running around. It was incredible to see the transformation.”

Dr. Conrad sums up Cassandra’s approach to her surgeries: “If you do it carefully, kids tolerate multiple surgeries really well. Little kids are pretty courageous; they have some anxieties but they don’t have any fear.”

### **An incredible gift**

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Carol has been patient with the drives back and forth from Spokane to Seattle for appointments and surgeries, and the long recovery periods. “As long as the cancer stays away,” she says, “we’ll deal with the little things.”

She adds that before Cassandra’s cancer she had not known about tissue banking. “You hear about people donating a lung or a liver when they die, but I’d never heard of a tissue bank before, of a place that could provide donor bone to prevent amputations.

“You don’t realize how important donation is until you face something like this yourself. It’s such an incredible gift.”

### **A deep gratitude**

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Helping patients like Cassandra is a special mission for both Dr. Conrad and the Tissue Center. “We’ve become one of a handful of sources for osteochondral bone in pediatric and adolescent limb-sparing procedures,” explains Tissue Center director Margery Moogk. “In fact, we were established to do this. It was one of the specific needs in the community when Dr. Conrad established his practice here more than a decade ago.”

In the last ten years, the Tissue Center has distributed more than 1,300 osteochondral grafts for pediatric and adolescent recipients, giving many children the same chance for the happy, healthy and normal life that Cassandra, with her easy smile and lively spirits, clearly enjoys.

Like Carol Burris, Dr. Conrad feels deeply indebted to families who choose donation in a moment of tragedy. “The courage of parents who consent to donation when their child dies is nothing short of heroic,” he says.

When asked what she would say to families of young donors, Carol pauses and searches for words. “They don’t know how much they’ve given me,” she says. As Carol looks at Cassandra, hamming it up in the spring sunshine, an expression of delight transforms her face.

“Until you go through this you just don’t know how important this is. You can’t thank people enough; it’s right here at home.”



*Children are pretty courageous, says Doctor Conrad.*

